NEW YORK STATE SUPREME COURT
COUNTY OF ALBANY

ALBANY LAW SCHOOL, and
DISABILITY ADVOCATES, INC.

Petitioners and Plaintiffs,

Index No. 10371-08
RJI No.

v.

THE NEW YORK STATE OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES and DIANA JONES RITTER, in her official capacity as Commissioner of the New York State Office of Mental Retardation and Developmental Disabilities.

Respondents and Defendants,

MEMORANDUM OF LAW IN SUPPORT OF PETITION FOR RECORDS ACCESS

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PRELIMINARY STATEMENT

Petitioners/Plaintiffs, Albany Law School ("ALS") and Disability Advocates, Inc. ("DAI") (collectively "Petitioners"), are protection and advocacy agencies authorized by statute to investigate, advocate, and litigate on behalf of individuals with developmental disabilities and mental retardation. Petitioners' statutory mandate includes the right of access to records of the individuals whose rights they protect. In this action, Petitioners sue Respondents/Defendants (hereafter "Respondents") New York State Office of Mental Retardation and Developmental Disabilities ("OMRDD") and OMRDD Commissioner Diana Jones Ritter, for unlawfully denying them access to the clinical records of individuals with developmental disabilities residing in New York State facilities operated by OMRDD. This civil action is both a petition pursuant to CPLR Article 78 and a suit pursuant to 42 USC § 1983 to enforce Petitioners' rights of access to the clinical records under federal law.

The New York State Office of Mental Retardation and Developmental Disabilities has refused to afford Petitioners access to records within its sole possession concerning the treatment of patients within its care, notwithstanding state and federal law which requires OMRDD to provide those records to Petitioners. Petitioners' rights of access to records arise under laws enacted to ensure appropriate care and treatment of persons with mental retardation and developmental disabilities, and to prevent the recurrence of abuses that were widespread for many years. Respondents' denial of such access unlawfully restricts Petitioners' ability to provide the effective, independent oversight that the law requires, and threatens the rights and well being of the individuals that Petitioners have a duty to protect.

STATEMENT OF FACTS

In the 19th Century and for much of the 20th Century, individuals with developmental disabilities were generally housed in New York State public institutions, separated from their communities and families. Over the years, these state schools and asylums became rife with abuse, neglect and squalid conditions of confinement that were sustained by a veil of secrecy which prevented public outcry and demands for change. In 1964, New York State and federal legislators toured a facility in New York and reported shocking mistreatment of its residents. While the legislators were struck by the "vile stench" of the facility and the "crude way of life" forced upon its residents, these impressions were kept secret and the conditions continued to be hidden from public view. Joint Legislative Committee on Mental Retardation and Physical Handicaps, Confidential Report, at 15, 18, 24 (Sept. 12, 1964).

Finally in 1972, Bernard Carabello, a resident at the Willowbrook State School for the past eighteen of his twenty-one years, met with reporters and exposed the rampant abuse and neglect at that facility. Despite his lack of education and nearly two decades of abuse and neglect, Bernard awoke the world to the horrific treatment of individuals with mental retardation. *See* David J. Rothman & Sheila M. Rothman, *The Willowbrook Wars Bringing the Mentally Disabled into the Community* 43-44 (Aldine Transaction 2005) (1984); *Forgotten Lives: Bernard*, video at http://www.youtube.com/watch?v=qZFTQ3_04i0.

In 1977, in response to these inhumane conditions, New York created the Commission on Quality of Care (now the Commission on Quality of Care and Advocacy for Persons with Disabilities) (referred to herein as "CQC-APD", "CQC" or "the Commission"), a state agency responsible for independently investigating complaints of

abuse or neglect within state operated facilities for individuals with disabilities and for the ongoing monitoring of those facilities. *See* Mental Hyg. Law § 45.01 (Consol. 2008). The creation of CQC-APD was designed to detect and prevent abuse, neglect and unnecessary institutionalization from reoccurring.

Eventually the federal government also took action. Congress created a Protection and Advocacy system to safeguard the human and civil rights of individuals with disabilities. 42 U.S.C. §§ 6000 - 09; P.L. 98 – 527, *repealed by* Developmental Disabilities Assistance and Bill of Rights Act of 2000, Pub. L. No. 106-402 (42 U.S.C. §§ 15001-09). Federal funding was made available to enable each state to develop a Protection and Advocacy ("P&A") agency, much like CQC-APD in New York, which would monitor the services provided to individuals with developmental disabilities and investigate allegations of abuse and neglect.

<u>The New York Protection and Advocacy System</u>

In 1980, Governor Carey, designated CQC-APD as the P&A agency for New York State. The Developmental Disabilities Assistance and Bill of Rights Act ("DD Act") which authorizes the P&A system, requires the P&A to investigate, advocate and, when appropriate, litigate to protect individuals with disabilities. 42 U.S.C. § 15043(a)(2)(A)(i). In furtherance of its mission, CQC-APD has contracted with not-for-profit law offices throughout New York State. These contracts authorize these offices to act as protection and advocacy organizations.

Disability Advocates, Inc. and the Civil Rights and Disability Law Clinic at Albany Law School ("CRDLC") have for decades been designated as P&A agencies through such contracts with CQC-APD. These contracts enable CQC-APD to expand its

capacity for investigating abuse and neglect complaints, and ensure that the P&A system in New York can pursue any and all legal remedies for its clients with complete independence.

CRDLC's contract with CQC-APD authorizes it to provide Protection and Advocacy for Individuals with Developmental Disabilities ("PADD"). DAI serves as a PADD agency by a CQC-APD approved contract with Albany Law School. DAI also has a contract with CQC-APD which authorizes it to provide protection and advocacy services for persons with mental illness throughout New York State under the Protection and Advocacy for Individuals with Mental Illness Program ("PAIMI"); for persons with other disabilities in the upper Hudson Valley Region under the Protection and Advocacy for Individual Rights Program ("PAIR"); and to disabled recipients of Social Security benefits in the Greater Hudson River Valley under the Protection and Advocacy for Beneficiaries of Social Security Program ("PABSS").

The New York State Legislature enacted Mental Hygiene Law §§ 33.13 and 45.09 which grant broad access to facilities and records to the agencies under contract with CQC-APD, including the Petitioners. This law is necessary to permit monitoring and investigations that would prevent abuse and neglect from occurring undetected.

Current Conditions in New York Facilities

While conditions in New York's facilities for individuals with developmental disabilities have improved, instances of abuse continue. For example, in October 2007, two staff members at O.D. Heck Developmental Center, an OMRDD residential facility that provides treatment and care for individuals with mental retardation and developmental disabilities, were convicted of manslaughter after they improperly

restrained 13 year old Jonathan Carey, a disabled resident of the institution, causing him to stop breathing. The staff members failed to respond to Jonathan's condition as they drove around in a van for approximately 90 minutes – running errands, buying beverages and shopping – while Jonathan died in the backseat. Robert Gavin, *Killing Time as Life Came to an End, Former Health Aide Says Co-worker Did Errands After Boy in Their Care Stopped Breathing*, Times Union (Oct. 5th 2007), *available at,* http://timesunion.com/AspStories/story.asp?storyID=627541&category=jonathan &BCCode=&newsdate=1/7/2009 (accessed January 7, 2009).

This was not the first time Jonathan Carey had suffered abuse. When Jonathan was a resident of an OMRDD licensed facility, his parents alleged that he was confined for weeks in his room; left to lie naked in a urine soaked bed; deprived of food; not permitted to have toys, books or other items he enjoyed; and that his windows were covered with paper to prevent him from seeing out. A June 2008 report by the New York State Inspector General investigating these allegations underscores the important role played by outside agencies like the Petitioners in monitoring OMRDD facilities to detect abuse and neglect. Joseph Fisch, State of New York Office of Inspector General, *A Critical Examination of State Agency Investigations into the Abuse of Jonathan Carey: Executive Summary* (June 2008), *available at,* http://www.ig.state.ny.us/pdfs/Jonathan %20Carey%20Report-Executive%20Summary.pdf (accessed January 7, 2009). The June 2008 Inspector General report summarizes the investigation into allegations that CQC-APD and OMRDD failed to properly investigate allegations of abuse and neglect concerning Jonathan Carey. The Inspector General found that OMRDD obtained evidence of very serious violations which were not included in OMRDD's Statement of

Deficiencies. The Inspector General found that OMRDD failed to mention potential violations of regulations prohibiting seclusion, unauthorized time out, and neglect, all of which are classified as abuse under OMRDD regulations. *Id at 11*. OMRDD Commissioner Diana Jones Ritter accepted the findings. Statement from OMRDD Commissioner Diana Jones Ritter Regarding the Release of the IG Report "*A Critical Examination of State Agency Investigation into allegations of abuse of Jonathan Carey*" (June 11, 2008), *at* http://readme.readmedia.com/news/show/Statement-from-OMRDD-Commissioner-Diana-Jones-Ritter-Regarding-the-Release-of-the-IG-Report/195241 (accessed January 7, 2008). The Inspector General's report provides a powerful reminder that abuse and neglect will not be prevented and remedied without both appropriate internal investigations by OMRDD and independent oversight by CQC-APD and Petitioners.

Petitioners' Current Investigation

In 2004, CRDLC initiated an investigation into the care and treatment of individuals residing at O.D. Heck Developmental Center, an OMRDD residential facility that provides treatment and care for individuals with mental retardation and developmental disabilities. Initially, the investigation concerned the lack of an educational program at O.D. Heck despite the fact that many of the residents were adolescents. During the course of this investigation, the psychologist in charge of the adolescent unit at O.D. Heck revealed that many of the residents would benefit from living in a community residence and did not require the intensive residential supports provided by the institution. This was confirmed by other members of the treatment team and the administration. Further investigation by CRDLC revealed that OMRDD lacked

any clear policies or procedures to facilitate the move of these adolescents into community residences. By the end of 2004, this investigation was expanded to include the adult units in the facility at which the same problems ultimately were found.

In early 2005, OMRDD granted CRDLC access to the records for all of the residents of both the adolescent and the adult units at O.D. Heck. The records revealed a pattern and practice of needlessly segregating individuals with mental retardation in public institutions, rather than placing them in more integrated community settings. Indeed, while the investigation revealed that many of the residents were deemed by their treatment teams as ready to live in a community placement with the appropriate supports and services, there was virtually no activity to transfer them to community settings. The investigation also found that OMRDD had no policy or training documents regarding indentifying individuals who are ready for discharge and moving them to the community. Rather, regional DDSOs were left to improvise a process on their own.

In the summer of 2006, CRDLC continued negotiations with OMRDD regarding the lack of statewide policies and procedures to facilitate community integration of developmental center residents. Given the scope of the deficiencies, CRDLC solicited the assistance of DAI and the pro bono representation of Patterson Belknap Webb & Tyler LLP ("Patterson Belknap").

In July 2007, in the course of these negotiations, OMRDD Deputy Commissioners Max Chumera and Patricia Martinelli informed Petitioners that OMRDD was planning on changing their computerized tracking system (the "Tabs System") to include the ability to track an individual resident's readiness for discharge. The tracking system would also measure the duration of the planning process from the time of the

treatment team's decision to discharge, until the individual's entrance into a community residence. Petitioners were told to anticipate that the modified tracking system would be active by the fall of 2007. Upon learning of this modified tracking system, Petitioners requested that they be allowed access to the data generated as it pertained to individuals residing in OMRDD facilities. The Petitioners explained that only by reviewing this information could they assess if progress had been made on the discharge process. OMRDD Deputy Commissioners questioned Petitioners' authority to access the data of the Tabs System and stated that any data OMRDD shared with the Petitioners would likely have to be redacted. However, in good faith efforts to negotiate access, it was agreed by all parties that no final decision had been reached and that the issue would be decided at a later date.

In July of 2008, the parties met again. While the tracking system had still not been implemented, the OMRDD Deputy Commissioners stated that they anticipated that the system would be up and running by the end of October 2008. During the same meeting, Petitioners requested access to the data from the tracking system in order to fulfill Petitioners' monitoring responsibilities. Again the completeness of the information that would be shared with the Petitioners was not resolved, but Deputy Commissioner and Counsel to OMRDD, Patricia Martinelli, assured Petitioners that she would provide a written response to Petitioners' request within a few weeks of this request. Despite learning that the Tabs System became operational in November 2008, Petitioners have not been given access or received a response to its request for access to Tabs system data from OMRDD. On November 21, 2008, Patterson Belknap Webb & Tyler on Petitioner's behalf sent a letter to Deputy Commissioner Martinelli reviewing

Petitioners' request for Tab reports. *See* Exhibit A of the Affidavit of Bridgit M. Burke (hereafter "Burke Affidavit"). By letter dated November 21, 2008, Deputy Commissioner Martinelli responded promising to send Petitioners the Tab reports. To date Petitioners have not received a Tab report. *See* Exhibit B Burke Affidavit.

In tandem with Petitioners' requests for access to the data from the Tabs System, during the summer of 2008 CRDLC again requested access to records for the annual reviews and placement planning activities for all of the individuals currently residing at O.D. Heck. *See* Exhibit C Burke Affidavit. Subsequently, on August 7, 2008, DAI requested access to the clinical records of all individuals residing at the Taconic DDSO. *See* Exhibit D of the Affidavit of Jennifer J. Monthie (hereafter "Monthie Affidavit").

On August 29, 2008 Deputy Commissioner Patricia Martinelli, sent a letter to Petitioners denying the requests, but for a handful of records. *See* Exhibit E Monthie Affidavit. Petitioners were denied access to the records for individuals who apparently did not have the capacity to consent, and for whom there was no family member who had the authority to consent to the release of the records.

On December 9, 2008 Petitioners informed OMRDD of its intent to file this action to compel disclosure if the parties could not reach resolution prior to December 19, 2008. *See* Exhibit H Monthie Affidavit. On January 5, 2009, after papers in this action had been filed, Deputy Commissioner and Counsel, Patricia Martinelli wrote Petitioners confirming that OMRDD's position with respect to access to records had not changed. *See* Exhibit F of the Affidavit of Bridgit M. Burke, Esq.

Petitioners are engaged in ongoing negotiations with OMRDD to address the lack of appropriate policies and procedures for deinstitutionalization. It is impossible to

assess whether significant progress has been made in this regard because OMRDD has continually refused to provide CRDLC and DAI with access to many of the residents' records.

This denial represents a violation of both New York State Mental Hygiene law and the Developmental Disabilities Rights Act.

I. Under New York's Mental Hygiene Law, the Denial by Respondents of Access to the Mental Health Records Was Arbitrary and Capricious and Contrary to Law

New York Mental Hygiene Law requires that OMRDD keep the clinical records of individuals residing in its facilities confidential absent a specific provision in the law authorizing the release of such records. Mental Hyg. Law § 33.13 (Consol. 2008). Section 33.13 (c)(4) of the Mental Hygiene Law, is an exception to this prohibition, as it requires the release of clinical records to the CQC-APD and any agencies that provide protection and advocacy services under contract with CQC-APD. The records must be provided upon request – the statute requires no more. Mental Hyg. Law § 33.13(c)(4). Petitioners must keep these records confidential to the same degree that OMRDD must keep them confidential. Mental Hyg. Law § 33.13(f).

Another exception to the prohibition on the release of confidential records is § 45.09(b) of the Mental Hygiene Law. That section requires OMRDD to grant CQC-APD and any agencies that provide protection and advocacy services under contract with CQC-APD access to its facilities and access to all of its books, records, and data. These records, books and data must be provided upon receipt of a complaint by or on behalf of a person with a disability. Petitioners must keep these records confidential to the same

degree that OMRDD must keep them confidential. Mental Hyg. Law § 45.09(b) (Consol. 2008).

The petitioners, CRDLC and DAI, are both agencies that provide protection and advocacy services under contract with CQC-APD and they are therefore entitled to access the records of any individual residing in an OMRDD facility. Petitioners have made requests for the release of records of individuals residing in facilities operated by OMRDD pursuant to § 33.13(c)(4) of the Mental Hygiene Law, but have been denied access save for the records of a handful of residents.

Petitioners are also entitled to access to OMRDD's Tabs System, a data collection system used to track the discharge process for individuals residing in OMRDD residential facilities. Petitioners are protection and advocacy agencies under contract with CQC-APD and have received a complaint on behalf of individuals with disabilities residing in OMRDD's residential facilities. In the course of Petitioners investigation of these residential facilities they uncovered: the denial of rights to live in less restrictive settings, the failure to provide necessary treatment that would prepare and enable individuals with disabilities to live in such settings, and the failure to implement discharge plans. Thus Petitioners are entitled to the TABS records pursuant to § 45.09(b). Respondents have failed to provide the data.

Respondents appear to justify this action by claiming that while the law would allow for the release of all of the requested records to CQC-APD, contracting agencies' access is limited to that provided by federal law. Respondent's contention, however, is belied by both the plain meaning of the statute and its extensive legislative history.

Section 33.13(c)(4) states:

> Such information about patients or clients reported to the offices, including the identification of patients or clients, and clinical records or clinical information tending to identify patients or clients, at office facilities shall not be public record and shall not be released by the offices or its facilities to any person or agency outside of the offices except as follows: to the commission on quality of care for the mentally disabled and any person or agency under contract with the commission which provides protection and advocacy services pursuant to the authorization of the commission to administer the protection and advocacy system as provided for by federal law.

Mental Hyg. Law § 33.13(c)(4) (Consol. 2008).

Similarly, § 45.09(b) of the Mental Hygiene Law states in unequivocal terms:

> Pursuant to the authorization of the commission to administer the protection and advocacy system as provided for by federal law, any agency or person within or under contract with the commission which provides protection and advocacy services must be granted access at any and all times to any facility, or part thereof, serving a person with a disability operated or licensed by any office or agency of the state, and to all books, records, and data pertaining to any such facility upon receipt of a complaint by or on behalf of a person with a disability.

Mental Hyg. Law § 45.09(b) (Consol. 2008).

Where, as here, the words of a statute are unambiguous there is no need to look to legislative intent. N.Y. Gen. Constr. Law § 76 (Consol. 2008). However, even if the Court were to consider the legislative intent of the statute, it would be compelled to conclude that OMRDD's denial of access is improper.

The 1984 version of the Developmental Disabilities Act, Public Law 98-527, required each state to ensure that the Protection and Advocacy program would have the access that it needed under federal law. In fulfillment of this requirement in March of 1985 Governor Cuomo and the Chairman of the CQC signed an assurance that:

> [T]he Commission, pursuant to Sections 33.13 and 45.09 of the New York State Mental Hygiene law, has access at any and all times to the records of

> persons with developmental disabilities residing in State-operated and licensed mental hygiene programs. Further clarification, including legislative amendments, will be sought to ensure access by the Protection and Advocacy Program contract agencies consistent with the requirements of Public Law 98-527...

S. 7578-A, at 5 (N.Y. 1986) (Assurances by the Governor of the State of New York for the Protection of Rights and Advocacy for Persons with Developmental Disabilities); Exhibit A Monthie Affidavit.

In February of 1986, CQC sought legislative amendment of § 33.13. Counsel Paul Stavis' memorandum in support of the Act opined that:

> Section one of the proposal would amend Section 33.13(c)(4) of the Mental Hygiene Law to provide access to clinical records of mental hygiene facilities to agencies under contract with the Commission on Quality of Care for the mentally disabled to provide protection and advocacy services.

S.7578-A, at 8 (N.Y. 1986) (Memorandum of Paul Stavis, Counsel to CQC-APD); Exhibit A Monthie Affidavit.

In his memorandum, Mr. Stavis also expressed the view that the law already in existence provided CQC with the authority to access clinical records and that the amendment was necessary to provide the same level of access to the contract agencies:

> Section 33.13 of the Mental Hygiene Law specifically authorizes the Commission to obtain access to clinical records of mental hygiene facilities. This particular provision provides no such authorization for the Commission to expressly delegate this authority to the Protection and Advocacy agencies which are under contract with the Commission.

Id.

Mr. Stavis further commented that:

> The authority of agencies under contract with the Commission through Protection and Advocacy Program is not clearly stated in Mental Hygiene Law. Furthermore, during the past year, the Commission had difficulty accessing records involving an individual living in a facility for developmentally disabled individuals certified by an agency outside of the Department of Mental Hygiene. Access to the records of clients in these

facilities by the Protection and Advocacy Program must be assured in order to comply with the Developmental Disabilities Act of 1984.

Id. at 9.

After the amendment was passed by the legislature and was awaiting the signature of the Governor, Paul Kietzman, then General Counsel for OMRDD, wrote a letter to the Governor's counsel on behalf of OMRDD voicing the agencies' strong opposition to the bill. In his letter Mr. Kietzman correctly identified that the amendment "[W]ould provide access to clinical records of mental hygiene facilities to agencies under contract with the Commission on Quality of Care for the Mentally Disabled to provide protection and advocacy services." Mr. Kietzman went on further to say that OMRDD's position was that:

> the system to permit access to client's records is in place. The Commission, pursuant to Mental hygiene Law §33.13(c) (4), presently has access to these records. Therefore, to extend this access to all persons and agencies under contract with the Commission is unnecessary... Moreover, the amendment, as it now asserts, would tolerate access if a complaint was received by or on behalf of an individual with a mental disability, even if that individual has a legal guardian. In the [Developmental Disabilities Rights] Act, access is only required if a complaint has been received and if such person does not have a legal guardian. The amendment enlarges the scope of access required by the [Developmental Disabilities Rights] Act.

S. 7578-A, at 20-21 (N.Y. 1986) (Letter from Paul Kietzman, General Counsel to OMRDD to Hon. Evan A. Davis, Counsel to the Governor); Exhibit C Monthie Affidavit.

Mr. Stavis also wrote to the Governor's Counsel on behalf of CQC urging him to sign the bill. He too clearly stated that a primary goal of the amendment was to:

> enable the agencies under contract with the Commission as part of this protection and advocacy program, to obtain access to mental hygiene residential facilities and client records allowed to the Commission itself under current law.

S.7578-A, at 12 (N.Y.1986) (Letter from Paul Stavis, Counsel to CQC-APD to Hon. Evan A. Davis, Counsel to the Governor); Exhibit B Monthie Affidavit.

Despite the clear objections of OMRDD and with the benefit of CQC's support, the Governor approved the amendments to the Mental Hygiene law providing offices like Petitioners with the same access to facilities and patient's records that CQC enjoyed prior to the amendment.

Now, over twenty years later, OMRDD claims that the law is unclear and that the intention was to provide complete access to CQC, but limited access to the agencies under contract with that agency. The legislature and the Governor rejected OMRDD's view of what the law should be, and OMRDD must not be allowed to ignore the law and deprive Petitioners of the ability to investigate and monitor in order to detect and remedy abuse and neglect.

II. Federal Law Authorizes Petitioners Access to Records for All Individuals Without "Legal Representatives" When the Petitioner Believes there is Probable Cause to Investigate Allegations of Abuse and Neglect.

Respondents have not even allowed Petitioners access to all of the records that they are entitled to under the DD Act. In so doing, the Respondent has prevented the Petitioners from investigating and remedying allegations of abuse, neglect and unnecessary institutionalization. The responsibilities of a Protection and Advocacy agency under the federal Act include:

- Investigating incidents of abuse and neglect when the P&A determines that there is probable cause to believe a complaint [42 U.S.C. § 15043(a)(2)(B)];
- Monitoring the care and treatment provided to individuals with disabilities [45 C.F.R. § 1386.22(g)];

- Pursuing administrative, legal and other appropriate remedies or approaches to ensure the protection of rights of eligible persons with disabilities [42 U.S.C. § 15043(a)(2)(A)];
- Providing information, referral and training concerning programs and services addressing needs of eligible individuals, and training about individual rights and services available from the P&A *Id.*

A. Petitioners' Have the Authority to Investigate When the P&A Determines that Allegations of Abuse and Neglect Demonstrate Probable Cause.

CRDLC and DAI are both authorized P&A agencies under contract with CQC-APD. Both agencies are authorized Protection and Advocacy for individuals with Developmental Disabilities ("PADD") offices. A protection and advocacy agency's authority to investigate is triggered when the agency deems that it has probable cause to suspect abuse or neglect. 42 U.S.C. § 15043(a)(2)(I)(ii)(III). The definition of "probable cause" is defined in the pertinent PADD regulations as:

> Probable cause means a reasonable ground for belief that an individual with developmental disabilities has been, or may be, subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experiences or training regarding similar incidents, conditions or problems that are usually associated with abuse or neglect.

45 C.F.R. § 1386.19

"Probable cause" under the P&A Act is not bound by – and indeed is broader than – "probable cause" for criminal investigations under the Fourth Amendment because these investigations do not threaten a constitutionally protected right. *Alabama Disability Advocacy Program v. Tarwater*, 97 F.3d 492, 497-498 (11th Cir. 1996). Moreover, it is for the P&A alone, such as Petitioners here, to determine if there is probable cause:

> ...it is now a settled principle that the P&A is the 'final arbiter of probable cause for triggering its authority to access all records for an individual that may have been subject to abuse or neglect.'

Prot. & Advocacy Sys. v. Freudenthal, 412 F. Supp. 2d 1211, 1219 (D. Wyo. 2006), citing *Arizona Center for Disability Law v. Allen*, 197 F.R.D. 689, 693 (D. Ariz. 2000). See also, *Ctr. for Legal Advocacy v. Earnest*, 188 F. Supp. 2d 1251, 1257 (D. Co. 2002), reversed on other grounds, 320 F. 3d 1107 (10th Cir. 2003); *Protection and Advocacy for Persons with Disabilities v. Armstrong*, 266 F. Supp. 2d 303, 318 (D. Conn. 2003); *Iowa Prot. & Advocacy Servs. v. Rasmussen*, 521 F. Supp. 2d 895 (S.D. Iowa 2002); *Iowa Prot. & Advocacy Servs. v. Gerard Treatment Programs, L.L.C.*, 152 F. Supp. 2d 1150, 1159 (N.D. Iowa 2001); *Maryland Disability Law Center, Inc. v. Mt. Washington Pediatric Hospital, Inc.*, 106 Md. App. 55, 664 A. 2d 16 (1995).

Here, Petitioners have determined that there is probable cause to investigate the possible neglect of individuals residing in both the O.D. Heck and the Taconic DDSO's ICF-MR units stemming from the facilities administration and the individual treatment teams' failure to "...establish or carry out an appropriate individual program plan or treatment plan (including a discharge plan)..." *See* 45 C.F.R. § 1386.19 (defining "neglect").

B. The P&A is Entitled to Records Access When an Individual Does Not Have the Capacity to Consent and Does Not Have a "Legal Representative

When the P&A determines that there is probable cause to conduct an investigation, federal law grants them access to an individual's records if the individual or a legal representative consents to the release. However, in instances where the individual both does not have the capacity to consent and does not have a legal representative, then the facility is required to provide the P&A access to the individual's records.

If an individual cannot grant consent to release his or her records, the DD Act, 42 U.S.C. § 15043, provides that consent may be given by "a legal guardian, conservator, or

other legal representative". The DD Act regulations, 45 C.F.R. § 1386.19, expressly define these terms:

> Legal Guardian, conservator, and legal representative all mean an individual appointed and regularly reviewed by a state court or agency empowered under State law to appoint and review such officers and having authority to make all decisions on behalf of individuals with developmental disabilities. It does not include persons acting only as a representative payee, person acting only to handle financial payments, attorneys or other persons acting on behalf of an individual with developmental disabilities only in individual legal matters, or officials responsible for the provision of treatment or habilitation services to an individual with developmental disabilities or their designees.

45 C.F.R. § 1386.19

This limitation makes sense because there is no legal authority to consent to the release of the records unless the representative has been legally appointed or parent of minor children. The law in New York regarding access to records was clarified long ago by the Court of Claims. A parental relationship without appointment as a "legal representative" is insufficient to obtain access to records and, therefore, such a family member cannot grant access. *See Application of Bryant*, 105 N.Y.S. 2d 446 (Ct. of Claims, 1950; *In the Matter of Derek*, 12 Misc.3d 1132, 1131, 821 N.Y.S. 2d 387 (Surrogates Court 2006).

When Petitioners requested access to the records of individuals at the Capital District DDSO and the Taconic DDSO, OMRDD took the position that it would provide access to the records of individuals who did not have the capacity to consent and who did not have a legal representative. However, Respondents only released the records concerning a handful of individuals and denied records access for those residents who had family members who were not legal guardians. This denial violates both federal law and New York law. Since these family members have no authority to release these

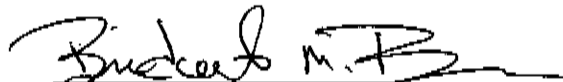
records to the Petitioners, it effectively bars the Petitioners from reviewing records of the majority of OMRDD's residents. The Petitioners, therefore, respectfully request that the Respondents be directed to grant access to the records for all individuals who either do not have capacity to provide their own consent or do not have a legally appointed representative who could authorize the release of the records.

CONCLUSION

As Protection and Advocacy agencies Petitioners are entitled to access the records of individuals residing in an OMRDD facility. Respondent's refusal to grant such access is in violation of state and federal law and thwarts Petitioners from fulfilling their obligations to individuals with developmental disabilities. Petitioners respectfully request that the relief requested in the attached Petition be granted.

Respectfully Submitted

Albany, New York
Dated: January 9, 2009



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